Children with septo-optic dysplasia – musical interests, abilities and provision: The results of a parental survey

Linda Pring* and Adam Ockelford+

* Psychology Department
Goldsmiths College
University of London
London SE 14 6NW

\+ Royal National Institute for the Blind
105 Judd Street
London WC1H 9NE

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Abstract

This paper reports the results of an exploratory survey of 32 families of children with septo-optic dysplasia and 32 families of children without visual impairment or any specific health problems (who served as a comparison group). The focus of the research was to explore the children's musical interests and abilities, the musical provision that was made for them, and the ways in which music might impact upon their wider development and education. The reports of the parents and carers provided a substantial amount of information and while the data may have been subject to certain biases, the findings nevertheless serve as an important signpost for future research. The main conclusions relate to the fact that, despite reportedly high levels of musical interest and ability among children with septo-optic dysplasia – consistently higher than in the case of their fully-sighted counterparts – few had access to appropriate music-educational or therapeutic support, compared to many of the comparison group who were able to take advantage of a wide range of musical opportunities. Within the group with septo-optic dysplasia, the educationally blind children often displayed significantly different characteristics from those who were partially sighted, and level of vision seemed to be a more important factor in influencing musical development than the presence of the septo-optic dysplasia syndrome itself. It was evident that further research is needed to explore the levels of musical interest and ability in visually impaired children with a range of other eye conditions and syndromes, and to investigate in more detail the important role that music may play in the promoting their wider development.

Introduction

Many researchers believe that music may be particularly important to blind and partially-sighted children, and, indeed, there is evidence that individuals with profound visual impairment have more efficient auditory perceptual processing skills than sighted individuals. Furthermore, both blind people and musicians have been found to have increased excitability in the neural systems associated with auditory processing compared to people who are sighted and non-musicians (Roder and Rosler, 2003). This may be because, in the absence of visual information, children who are blind have a heightened awareness of environmental auditory stimuli such as language and music (Butterworth, 1981). Interestingly, both language and music comprise acoustic signals organised into a prosodic and syntactic structure and both involve complex cognitive and motor processes (Patel and Daniele, 2003). In addition, there appears to be an increased prevalence of 'absolute pitch' in individuals who are blind (Ockelford, 1988; Welch, 1988).

'Absolute pitch' is the ability to recognise, label and remember pitch information without reference to an external standard (Baggaley, 1974). It is extremely rare: only 1 in 10,000 in the normal Western population is a possessor. It seems that early musical exposure or instruction can influence its development (Takeuchi and Hulse, 1993; Levitin, 1994). The ability to 'hear' and recall notes independently from each other may be especially important to 'musical savants' – individuals with exceptional musical talents in the context of low cognitive ability and autistic spectrum disorder (Miller, 1989; Treffert, 2000: Heaton, Pring and Hermelin, 2001). Absolute pitch is not a necessary component of musical ability or talent, and many professional musicians do not possess it, though recently Hamilton, Pascual-Leone and Schlaug (2004) reported a very much higher than expected prevalence amongst blind musicians, suggesting that more research is needed to understand the relationship between absolute pitch, visual impairment and musical processing.

This study grew out of a workshop on music and early communication that formed part of the FOCUS[1] UK Conference held in the summer, 2003. During the workshop, a number of parents reported that their children had what seemed to them to be unusually high levels of musical interest or ability, and the question was raised as to whether these characteristics were related to their medical condition: septo-optic dysplasia[2]. If so, what were the implications for parents, teachers, therapists and others?

Septo-optic dysplasia is a rare condition that occurs in approximately one in 16,000 children. It is defined as a combination of optic nerve hypoplasia (absent or small optic nerves), pituitary abnormalities and the absence of the septum pellucidum or corpus callosum – without which communication between areas of the mid-brain (such as the transfer of sensory information) is hampered. Among the likely effects of septo-optic dysplasia are visual impairment, hormonal problems, delayed development, behavioural difficulties and obesity. The type and range of symptoms can vary from mild to very severe (Mehta and Dattani, 2004).

Since the area was wholly unresearched, it was felt that, as a first step, the best way of proceeding would be through informal visits to meet some of the children and their families,[3] and the development of a questionnaire, which could be distributed either electronically or in hard copy to parents and carers in the UK and the US, largely (though not entirely) through the FOCUS families network. Inevitably, though, gathering information in this way had possible disadvantages too. First, the respondents were self-selecting through requests in *Focal Points*, Volume 2, Issue 3, and *Eye Contact*, 38, and, despite clear requests to the contrary, it was possible that an undue proportion of parents whose children were particularly musical or interested in music would participate in the study. Second, there was a potential lack of consistency in the way that the questions and activities would be tackled. Third, it could be that any reported characteristics were not specific to septo-optic dysplasia, but arose as a more general consequence of limited levels of visual functioning.

[1] 'For Our Children's Unique Sight' – a support network of families whose children have septo-optic dysplasia / optic nerve hypoplasia. The group can be contacted at http://focusfamilies.org/
[2] Cf. other possible associations, such as the purported link between *retinopathy of prematurity* and absolute pitch (Treffert, 2000).
[3] Seven children were visited at home or school by Adam Ockelford or Sally Zimmermann (RNIB Music Advisor) or both.

However, while it would clearly be important to acknowledge these factors in reporting the results of the survey, it was felt that the findings would still be relevant to the parents of children with septo-optic dysplasia.[4]

Methodology

The questionnaire

The questionnaire was designed to elicit a mixture of quantitative and qualitative information, concerned with biographical details, special interests and talents (musical and otherwise), communication, behaviours, sociability, personality, memory, intelligence and any other issues that parents wished to raise.[5] In addition, there were three sets of activities for parents to undertake with their children, pertaining to verbal fluency, 'odd one out' sounds and memory for number sequences. This gave a total of over 100 questions and activities.

The participants

Of the participants with septo-optic dysplasia, 18 (56%) were female and 14 (44%) were male – a reasonable reflection of the equal prevalence of the syndrome in boys and girls (Mehta and Dattani, 2004). The distribution of age and gender is shown in Figure 1: there were two children or more from every year between 0 and 8, as well as individuals who were 12, 17, 22, 23 and 27 at the time of completion of the questionnaire. The mean age was 6.9 (sd: 6.7) years.

Place Figure 1 and Figure 2 about here

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[4] Excerpts from the questionnaire and a full report of the findings are to be found in Ockelford, Pring, Welch and Treffert (2005).

[5] This account focuses on musical interests and abilities; no significant correlations were found between these and the other areas of development and personality that were examined.

The comparison group was matched as closely as was practicable in terms of gender, having 17 girls and 15 boys, and age, where the range was 1.4 years to 12.4, with a mean of 7.8 (sd: 3.0) years.[6]

Within the group of participants who had septo-optic dysplasia, the prevalence of four levels of visual functioning was established as follows: 'no vision' (seven participants or 22%), 'perception of light' (six participants or 19%), 'perception of shape/movement' (three participants or 9%) and 'partial sight' (16 participants or 50%). The first three levels will be referred to here as 'blind'. Fifty-percent of participants were in this category. Other disabilities identified by parents were 'developmental delay' (six participants or 19%), 'autism' (three participants or 9%) and 'learning difficulties' (two participants or 6%). In 19 cases, there were no additional disabilities.

Results

Parents' perceptions of their children's interest in everyday sounds and music

Parents' perceptions of participants' interest in everyday sounds and music were probed and in response to the question 'Is your child particularly interested in everyday sounds (for example, vacuum cleaners, car engines)?', replies of 'a lot' were given on behalf of six of the seven totally blind participants (86%), four of the six participants with perception of light (67%), two of the three participants with perception of shape/movement (67%), five of the 16 partially-sighted participants (31%) and four of the 32 controls (13%).

[6] So although there was substantial overlap in the age profiles of the two groups, there were important differences too, whereby the participants with septo-optic dysplasia covered a greater range, with an emphasis on the early years. In summary, the controls were more tightly clustered around their mean age, which was approximately a year higher than the group with septo-optic dysplasia. Despite the differences in the age profiles of the two groups, the researchers considered that it was reasonable to draw straightforward comparisons between them in relation to certain issues: where age was clearly not a factor, for example, where parents were asked to reflect on what their children did at a particular age, or where they were asked to make judgements that took into account how old their child was. In relation to some other issues, however, age clearly was an important factor, and where this is so, it is considered as a discrete element in the analyses that follow. Although the fact that in a number of cases a participant's *functional* age differed from his or her *chronological* age due to developmental delay or learning difficulties needs to be born in mind.

These frequencies were compared through a series of Chi square analyses. Although the numbers were relatively small the pattern was clear; children who were blind showed a significantly greater interest in environmental sounds than did the either the children who were partially sighted ($p \leq 0.025$) or the sighted controls ($p \leq 0.01$).

With regard to an interest in music, the response 'a lot' was given in relation to all blind participants (16 out of 16, or 100%), 13 of the 16 who were partially sighted (81%) and 12 of the 32 controls (38%). Chi square analyses again showed that there was significantly more interest in music amongst the children who were blind compared to those who were fully sighted ($p \leq 0.001$), and this was also true for the partially-sighted group ($p \leq 0.01$). However, there was no significant difference between the reported levels of musical interest among the blind and partially-sighted participants, and within these groups, neither additional disabilities, gender nor age was found to have a significant effect.

There were no significant differences between the *type* of music young people with septo-optic dysplasia preferred relative to the fully-sighted group, as might be expected from children with similar cultural backgrounds, since such preferences seem to result from a complex cocktail of exposure, predisposition and an evolving sense of identity (Tarrant, Hargreaves and North, 2002).[7] Among the comparison group 13 (41%) parents reported children to have particular preferences, a proportion that was statistically similar to the 17 cases (53%) in the group with septo-optic dysplasia.

[7] Stylistically, these varied from 'classical' to rock and pop, from nursery rhymes to 'pub songs' and Bhangra. On a number of occasions, specific works were mentioned, ranging from 'Yankee Doodle' to the 'Blue Danube' waltz, or particular artists or groups, including Paul Weller, Simon and Garfunkel, The Who, Queen, Robbie Williams and Dido. One seven-year-old boy was reported to be wholly obsessed with the music of Rod Stewart. Children – particularly those in the early years or with learning difficulties – sometimes appeared to be attracted by a particular sound, such as the panpipes, women's voices or the drums, or by a certain dynamic ('loud music') or tempo (pieces with a 'fast beat'). A few dislikes were noted too: classical music ('too slow'), modern music ('too loud and raucous') and, in the case of one three-year-old, 'songs where a particular note is held for a long time'.

Parents' perceptions of the importance of music to their children in different contexts

Parents were asked whether they thought that music was or had been important to their son or daughter in a range of suggested contexts, in which music served as a source of stimulation or comfort, to promote communication, socialisation or understanding (for example, through 'counting' songs), or to mark out events in the daily routine. The results can be seen in Figure 3 (below).

Place Figure 3 about here

In the view of parents, blind children and young people with septo-optic dysplasia were significantly more likely to find music important for stimulation, comfort, communication, socialisation, understanding or to mark out daily events than their fully-sighted peers (all comparisons on Chi square were $p \leq 0.01$ or greater). Although in each context the partially-sighted children scored higher as a group than those who were fully sighted, the differences failed to reach significance.

The children's musical abilities: parents' perceptions and other evidence

Parents were asked whether, in their opinion, their child's musical ability was 'not as developed as you would expect for her/his age', 'about what you would expect for her/his age', 'more developed than you would expect for her/his age', or 'exceptionally highly developed'. Table 1 below provides the pattern of responses given by the parents.

Place Table 1 about here.

It is clear from the responses that the parents of the fully-sighted group considered their children to be generally average and the overall pattern differed significantly from both the blind ($p \leq 0.001$) and the partially sighted group ($p \leq 0.025$). Viewing the data in Table 1, these levels of significance tie in with the fact that 73% of parents whose children were blind judged them to be exceptional, or more than averagely developed, in terms of musical ability. The parents' perceptions of the children who were partially sighted fell between the other two groups, presenting a picture of both lesser- and greater ability than the average. No significant effects were found for gender, age or general level of development. The question of absolute pitch was probed too, but unfortunately the responses were found to be unreliable (as judged by the comments of the parents).

No differences of statistical significance emerged between the groups in terms of the particular times when or particular activities in which the children found music to be important. Many mentioned car journeys and bedtime. The number of responses to the question of how much time was spent on 'making music' was relatively low and useful comparisons between groups was not possible. Table 2 shows the results collapsed across the visual status of the children with septo-optic dysplasia. Only one parent (referring to a child from the blind group) explicitly mentioned an 'obsessive' interest.

Place Table 2 about here

Given the importance that music is thought to have for many children and young people with septo-optic dysplasia and their perceived levels of musical interest and ability, few of them received specialist musical input. With regard to music therapy, for example, only six of the 32 (19%) participants, of whom four had additional needs, were said to have (or to have had) sessions. Moreover, the nature of the therapeutic activity evidently varied considerably from one child to another. Some of the sessions appeared to be on a one-to-one basis, while others involved a group. For instance, a three-year-old girl with no additional disabilities 'attended a music group

with singing and instruments once a week for three eight-week sessions. This really helped her rhythm and her speech blossomed through singing.' Some descriptions of the therapy seem to indicate that in reality what was being offered was music education – a lack of conceptual clarity that is characteristic of the field in the UK (Ockelford, 2000).

None of the children with septo-optic dysplasia was reported to have instrumental lessons, compared with 28% of the comparison group. Nonetheless, seven of the participants with septo-optic dysplasia were said to play an instrument (22%),[8] with two being described as able to play two instruments. This contrasts with 13 of the controls whose parents indicated they played an instrument (41%), with five of them playing two. In answer to the question 'Is [your child] self-motivated to play or only when it is suggested?', 80% of those with septo-optic dysplasia (n=15) as opposed to 48% of the controls (n=23) replied in the affirmative, a difference which was statistically significant ($p \leq 0.05$).

Discussion and Conclusions

This project investigated the musical abilities and interests of children and young people with septo-optic dysplasia through the observations and views of parents and carers that were elicited via a questionnaire. One of the most important findings relates to the fact that on a number of occasions the results discriminated between the children who were blind from birth (and this group included children with some light and some shape perception) and those who were partially sighted. These two groups present with very different psychological profiles and are likely to differ in cognitive abilities (for example, Corley and Pring, 1993) and general rate of development (Warren, 2000; Lewis, 2002). The early childhood behaviours of children with congenital blindness and profound visual impairments have been referred to as being similar to those seen in children with autism (Hobson, 1993; Pring and Tadic, 2004). In this context it was interesting to find that the children who were blind differed from the other two groups in their interest in environmental sounds such as the noises made by a vacuum cleaner or washing machine. The interest of children with profound

[8] A further two were said to play *with* instruments (the keyboard and the drums).

visual impairments to such auditory stimuli may not be unexpected, given the lack of the visual channel. Indeed it has been reported that they have exceptional auditory abilities (see the introduction). Certainly, as noted above, there is a long-established association between music and visual impairment that is still far from understood. However it may be very important that the interest in 'environmental sounds' is shared with children with autism. These children have impairments in social interaction and communication along with repetitive and obsessive behaviours and restricted areas of interest (such as music, numbers and lists). While the data were unreliable in terms of developmental trends, it is worth noting that although the septo-optic dysplasia group's high level of interest in everyday sounds showed no sign of diminishing as the participants grew older (although with such small numbers no statistical differences were found), the few fully-sighted controls who were reported to share this fascination with sound were all in their early years, aged three or four. The increasing distractions afforded by the visual channel would be a likely contributor to this pattern. In the complete or near-complete absence of vision, sound offers a ready source of interest and stimulation. As one mother commented, her blind three-year-old daughter was interested in sounds of 'anything and everything since this is a huge part of her learning experience'.

Partially-sighted children reap the benefits that even degraded visual information can afford and may be protected from risk factors both in terms of early development (Dale, 2004) and other factors such as perception (Millar, 1995) and memory (Pring, 1988). Unfortunately, the problems of children who are partially sighted are often overlooked since there is little recognition of the extent of the visual loss and the attendant difficulties in terms of speed and accuracy of information processing (Corley, Robinson and Lockett, 1989).

While the results of the survey often discriminated between the visual status of the children, the findings were clear cut with respect to an interest in music. Here children with septo-optic dysplasia (all of whom had visual impairments) were reported to be significantly more interested in music than their sighted counterparts. The increasing distraction of vision with the start of formal education may play a role in this as well as the natural emphasis on music that the care-givers of children with visual impairments might provide in the context of communication. Joint attention

and theory of mind (Charman, 2003; Perner, Leekam and Wimmer, 1987) are important milestones in early development, and music surely provides an important medium for the processes to develop in the absence of sight. Several parents commented upon the pleasure of sharing music with their children. As one mother, speaking about her seven-and-a half-year-old daughter, put it: 'Her music is always with her. If there is not music playing, she is singing. She listens to music while in the car, while falling asleep, and loves to play the piano and any other instrument. It is definitely her strength in life.' Another simply said that her daughter was 'obsessed with music'. Among the group of 16 participants with septo-optic dysplasia who were blind, an exceptional interest in music, which included spending two hours or more a day in active music-making, was always present in reported cases of exceptional musical development. Yet according to parents, an exceptional interest in music did not necessarily lead to exceptional musical development. In the sample described here there did not appear to be any children who might begin to develop savant talents and so there is no information to be gleaned from the data that contributes to our understanding of the relationship between exceptional musical ability and visual impairment *per se* (though see below).

The musical ability of the children as gauged by their parents showed that in 73% of the sample those who were blind were perceived as displaying exceptional or more developed abilities than would be expected. It is significant that the judgements of the parents of children with septo-optic dysplasia differed significantly depending on whether their children were blind or partially sighted, and this helps to rule out the suggestion that the parents of children with sight problems used different criteria. Moreover, the pattern of results is in accord with Ockelford (1988). In his account of six such children with whom he worked as a specialist teacher, he indicated that two who were blind (of whom one had additional needs) had exceptional musical abilities. The musical development of a further two, of whom one was blind and one partially sighted, neither having additional educational needs, he judged to be broadly typical. The musical abilities of the remaining two, both of whom were partially sighted and with additional needs, were, in his estimation, less developed than those of most children of their age. Subsequently, the well-publicised accounts of eight-year-old

Rex Lewis-Clack[9] who has an outstanding ability to process musical sounds, remember what he has heard and reproduce the pieces he knows on the keyboard (in any key), have shown that even severe learning difficulties need be no barrier to exceptional musical achievement.

Despite their generally high reported levels of musical interest and ability, fewer of the children and young people with septo-optic dysplasia were said to play musical instruments (at any level). While these differences may in part be attributable to the differing age profiles of the two groups (more of the children with septo-optic dysplasia were in the early years), the data nevertheless suggest an important underlying trend that may be related to unduly low expectations of musical learning and achievement in the context of disability. For instance, although over a third of the children were said to have a 'special talent for singing', none received (or had ever received) vocal tuition. The proportion of children with septo-optic dysplasia who were reported to be self-motivated to make music was significantly greater than that of the controls and this would explain how the children actually learnt to play an instrument in the first place. Evidently, they were self-taught, and since none used any form of music notation (in braille or large print), they must have learnt pieces by ear or through visually copying what others did or both.

One conclusion that might fairly be drawn then from this survey of children with septo-optic dysplasia is that despite typically high levels of musical interest and ability that manifest themselves in a variety of contexts, few are given support in terms of musical tuition or therapy. Music may be able to help re-structure the environment for children with visual impairments (Ockelford, 1998a, 1998b), it may help to promote joint attention and through that increase the development of theory of mind (Hobson, 1993). It is clear we need to learn more about its potential multi-faceted roles in child development, but in the context of children with septo-optic dysplasia their natural affinity with the medium surely needs to be nurtured.

[9] For further information available on the web see
http://election.cbsnews.com/stories/2003/09/25/60minutes/main575161.shtml

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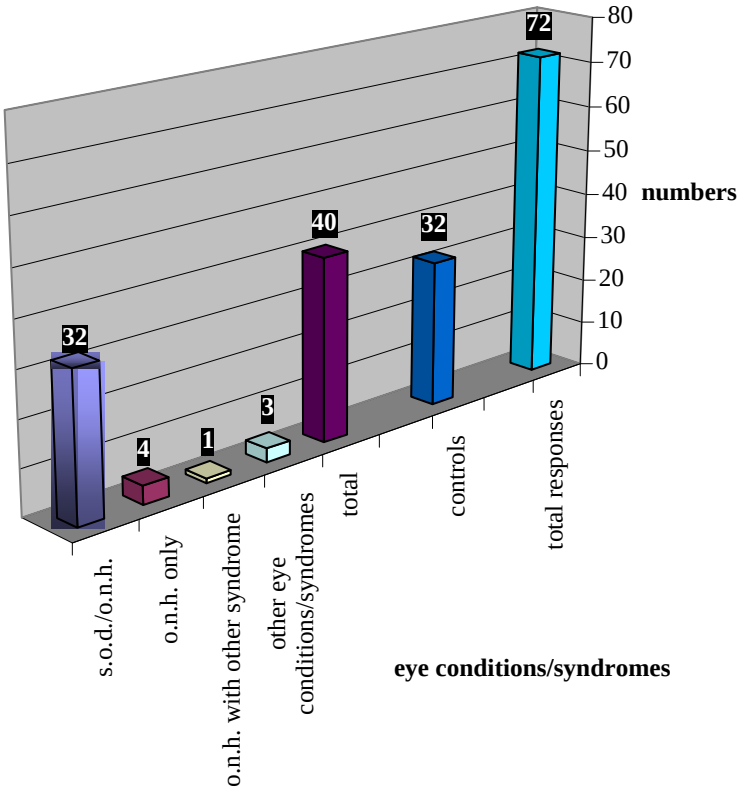
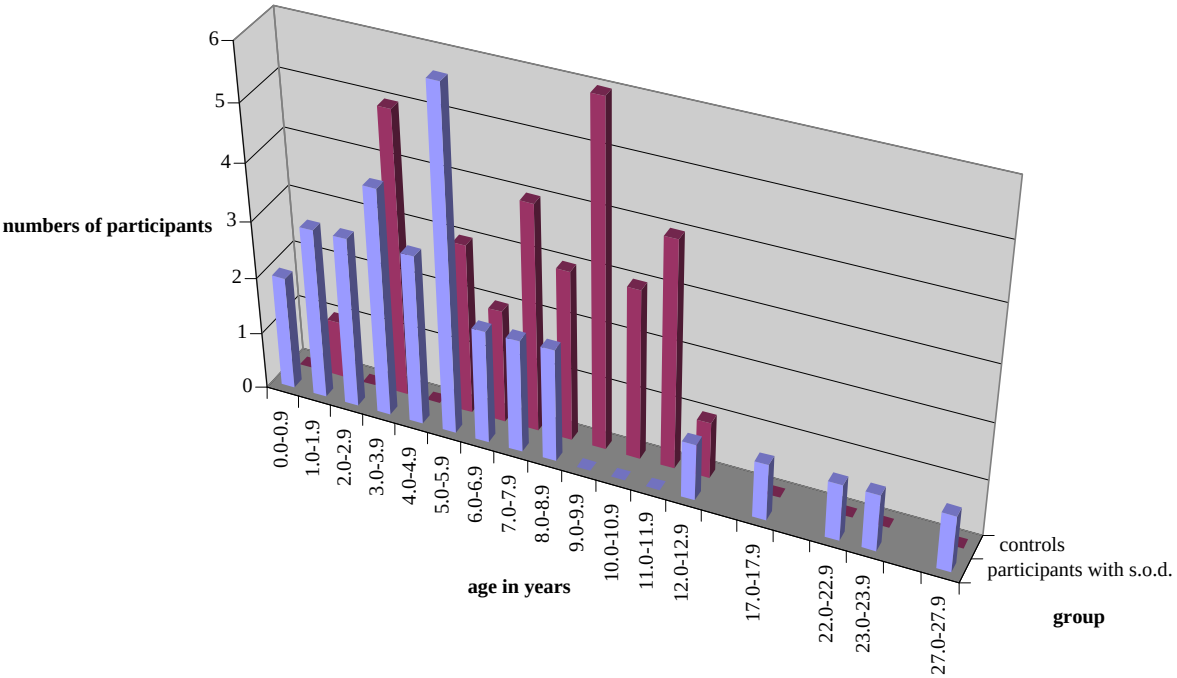
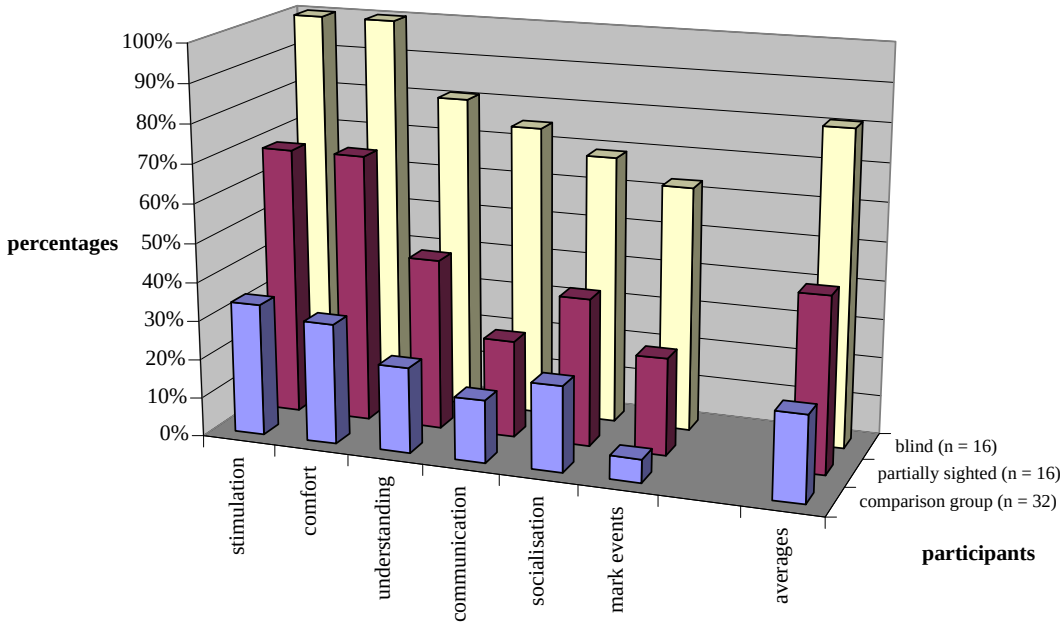


Figure 1 Numbers of participants in the research



	0.0-0.9	1.0-1.9	2.0-2.9	3.0-3.9	4.0-4.9	5.0-5.9	6.0-6.9	7.0-7.9	8.0-8.9	9.0-9.9	10.0-10.9	11.0-11.9	12.0-12.9		17.0-17.9		22.0-22.9	23.0-23.9		27.0-27.9
participants with s.o.d.	2	3	3	4	3	6	2	2	2	0	0	0	1		1		1	1		1
controls	0	1	0	5	0	3	2	4	3	6	3	4	1		0		0	0		0

Figure 2 Comparative age profiles



	stimulation	comfort	understanding	communication	socialisation	mark events		averages
comparison group (n = 32)	34%	31%	22%	16%	22%	6%		22%
partially sighted (n = 16)	69%	69%	44%	25%	38%	25%		45%
blind (n = 16)	100%	100%	81%	75%	69%	63%		81%

Figure 3 The perceived importance of music to participants

	blind (n = 14)	partially sighted (n = 14)	total s.o.d. (n = 28)	comparison group (n = 27)
less developed	14%	21%	18.0%	0%
typical	14%	43%	28.5%	81%
more developed	50%	36%	43.0%	15%
exceptional	22%	0%	10.5%	4%

Table 1 Parents' perceptions of their children's musical abilities

	s.o.d. responses (n = 16)	comparison group (n = 26)
0-1 hr	31%	69%
>1-2 hrs	25%	15%
>2-3 hrs	19%	8%
>3 hrs	25%	8%

Table 2 Lengths of time spent singing or playing each day.